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A qualitative study exploring the factors that influence the uptake of pre-pregnancy care among women with Type 2 diabetes

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What's new?

- In the UK, 90% of pregnant women with Type 2 diabetes are not adequately prepared for pregnancy, according to current guidelines.
- This study shows that the understanding and beliefs of women mediate their reproductive behaviours, that healthcare professionals, particularly in primary care, do not routinely engage women with Type 2 diabetes in productive conversations about pregnancy, and that current care systems fail to promote pre-pregnancy care.
- Awareness of pregnancy preparation in the context of diabetes needs to be embedded in routine Type 2 diabetes management for women of reproductive age, underpinned by education for women and professionals and enhanced healthcare systems.

Abstract

Aim To elicit the views and experiences of women with Type 2 diabetes and healthcare professionals relating to the pregnancy and pre-pregnancy care they have received or provided.

Methods A qualitative study using in-depth semi-structured interviews with women with Type 2 diabetes (*n*=30) and healthcare professionals (*n*=22) from primary and specialist care. Women were purposively sampled to include different experiences of pregnancy and pre-pregnancy care. Data were transcribed verbatim and analysed thematically using framework analysis.

Results The median age of the women was 37 years, and most were obese (median BMI 34.9 kg/m^2), of black or Asian ethnicity (*n*=24, 80%) and from areas of high deprivation (*n*=21, 70%). Participating healthcare professionals were from primary (*n*=14), intermediate (*n*=4) and secondary (*n*=4) care. Seven themes expressing factors that mediate reproductive behaviour and care in women with Type 2 diabetes were identified at the patient, professional and system levels. Type 2 diabetes was generally perceived negatively by the women and the healthcare professionals. There was a lack of awareness

about the pre-pregnancy care needs for this population, and communication between both groups was unhelpful in eliciting the reproductive intentions of these women. The themes also reveal a lack of systemic processes to incorporate pre-pregnancy care into the care of women with Type 2 diabetes, and, consequently, health professionals in primary care have limited capacity to provide such support.

Conclusion If the current high levels of unprepared pregnancies in women with Type 2 diabetes are to be reduced, the reproductive healthcare needs of this group need to be embedded into their mainstream diabetes management.

Introduction

Pregnancies in women with diabetes are associated with significant additional risks for the fetus, infant and mother [1–3]. To attenuate these risks it is important that women access effective pre-pregnancy care to optimize their glycaemic control, remove teratogenic medications and introduce high-dose folic acid [4]. While women with Type 2 diabetes account for half of pregnancies in women with pre-existing diabetes [5], they are much less likely to receive pre-pregnancy care than women with Type 1 diabetes [5]. Consequently, <10% of women with Type 2 diabetes in the UK are adequately prepared for their pregnancy according to current guidelines [4,5]. The failure to deliver pre-pregnancy care to this population elevates the risks of adverse pregnancy outcomes, with a fourfold increased risk of fetal demise [6] and double the risks of congenital malformation or still-birth [3,6–9] compared to women without diabetes. In addition, the National Pregnancy in Diabetes audit reported that in pregnancies of women with Type 2 diabetes a fifth result in macrosomia, over half require caesarean section, and many infants require neonatal care admission [5].

Interventions designed to address this deficit have only achieved modest improvements in the uptake of pre-pregnancy care among women with Type 2 diabetes [10,11]. For interventions to have more impact, we require a deeper understanding of the factors that influence the reproductive healthcare behaviours of women with Type 2 diabetes in the context of their current diabetes care. The primary

care perspective needs to be considered as this is where women with Type 2 diabetes receive their care. The limited qualitative data on women's views and experiences of pre-pregnancy care indicate that women's reproductive behaviours in the context of their Type 2 diabetes are complex and influenced by their relationship with the healthcare providers [12]. The aim of the present study, therefore, was to consider the experiences and views of women living with Type 2 diabetes, together with those of their healthcare professionals, on pregnancy and the provision of reproductive healthcare. It was envisaged that understanding these experiences would enable the development of more effective approaches for enhancing the uptake of pre-pregnancy care in this growing population.

Research design and methods

The study was designed using a qualitative approach, with individual in-depth semi-structured interviews to identify and explore phenomena related to the uptake of pre-pregnancy care among women with Type 2 diabetes. A framework analysis approach was selected as this enables an integrated analysis of heterogeneous subgroups, in this case women and healthcare professionals [13].

Ethics

Ethical approval for this study was granted by the National Research Ethics Service (Reference 14/NW/1511).

Sample and recruitment

Stratified purposeful sampling was used to ensure both symbolic representation [13] and specificity of participants experiences [14]. Thirty women with Type 2 diabetes were recruited from two South London boroughs with high levels of ethnic diversity, socio-economic deprivation and varying pregnancy and pre-pregnancy care experiences. A diverse sample of healthcare professionals was also

recruited. These included general practitioners (GPs), nurses working in general practice [practice nurses (PNs)], diabetes specialist nurses (DSNs) and diabetologists; *n*=22), involved in the care of women with Type 2 diabetes in primary, intermediate (community-based diabetes care) and specialist care settings in secondary care.

Data collection

Women with Type 2 diabetes were interviewed face-to-face, while healthcare professional interviews were conducted either face-to-face or via telephone, according to their own preference [14]. The women's interviews explored their understanding of pre-pregnancy care, the reproductive information they received, and their awareness of and/or access to pre-pregnancy care. The healthcare professional interviews focused on the pre-pregnancy and reproductive care they provided for women with Type 2 diabetes, their understanding of pre-pregnancy care, familiarity with national guidance, and their perceptions of the barriers to accessing pre-pregnancy care. All the interviews were conducted by the same researcher (R.F.). During the data collection period, interview transcripts and recordings were reviewed by the research team to ensure consistency across interviews and optimal interview technique and to capitalize on the emergent contributions of participants by identifying additional areas for exploration [13]. After each interview the transcript was appraised information power within the data based on the quality of the discourse. The collective data were subsequently appraised by J.C. and A.F. [14].

Data analysis

Transcripts were reviewed while simultaneously listening to the audio recordings to check for accuracy. They were then anonymized, pseudonyms were assigned and they were uploaded to NVIVO software version 10. Data from the women with Type 2 diabetes and the healthcare professionals were initially treated as discrete datasets and analysed independently. They were later synthesized to expose convergent themes related to the uptake of pre-pregnancy care. The framework analysis

followed five interconnected stages, as set out below [13]. The data transcripts were re-read in conjunction with contextual and reflective notes recorded by the interviewer.

1. Identifying an analytical framework. A preliminary framework derived from a synthesis of previous studies [12] was used as an initial reference, and subsequently adapted inductively reflecting new insights from the data; this was conducted iteratively and through discourse between members of the research team to support data interpretation and to attenuate researcher bias.

2. Indexing and sorting. Data extracts from all transcripts were linked to codes within the framework; again, this was done iteratively supported by team discussions.

3. Data summing and charting. Data were then 'charted' into the framework matrices in NVIVO, maintaining connectivity between the coded data and individual transcripts. Themes and sub-themes were then developed expressing key dimensions of the data.

4. Mapping and interpretation. The research team discussed the data as a whole, to ensure participants' accounts were accurately represented and that all relevant dimensions of the data were captured in identified themes.

Data analysis was conducted by R.F. and cross-checked with members of the research team; for divergent interpretations, consensus was reached through discussion.

Results

Participants

A total of 30 women aged between 25 and 44 years participated in the study: 17 with diabetes care delivered in primary care and 13 from secondary care (Table 1). Secondary care participants were recruited from pre-pregnancy clinics (*n*=5) and antenatal clinics (*n*=8). The majority of the women were overweight or obese, half were of black ethnicity and three-quarters were living in areas of high

deprivation. Women who had not accessed any pre-pregnancy care had lower educational attainment compared to those who had. The median (interquartile range) HbA_{1c} of the women was 57 (42–79) mmol/mol [7.4 (6–9.4)%]. The majority of the women were not using contraception, except for those who had previously attended pre-pregnancy care.

Interviews were conducted with 22 healthcare professionals from primary (GPs, *n*=6; PNs, *n*=8), intermediate (DSNs, *n*=4) and specialist care (DSNs, *n*=2; consultant diabetologists, *n*=2). Four of the GPs were diabetes leads in their practices, and six PNs had a diabetes remit within their role.

Themes

The convergent themes that emerged from the framework analysis are detailed below. Tables 2–7 present the themes, with related sub-themes and data excerpts from the women and healthcare professionals.

Lack of visibility of pre-pregnancy care in routine Type 2 diabetes care

The women's accounts highlighted that many had not received any focused input into how to consider their reproductive behaviours. The women reported that pregnancy did not feature in their initial education and was rarely raised in follow-up care. When pre-pregnancy care was addressed, the information provided was identified as uninformative and did not connect with their current pregnancy planning or contraceptive use (Table 2).

The healthcare professionals' accounts illustrated that pre-pregnancy care was not considered part of routine Type 2 diabetes care. As such they were not prompted to address the reproductive intentions/behaviours of the women. Pre-pregnancy care was not included in the electronic medical records system for Type 2 diabetes care, hence any conversations with women regarding their reproduction were documented in an *ad hoc* way using free text entries. The healthcare professionals

felt that the lack of a systematic record meant that reproductive issues were not followed up at subsequent appointments. In addition, the lack of a systematic record for pre-pregnancy care, limited any capacity for surveillance through clinical audits to assess practice performance and drive change in clinical practice (Table 2); hence, the absence of systematic pre-pregnancy care records reduced its visibility as an element of diabetes care.

Perceptions of Type 2 diabetes

The way Type 2 diabetes was perceived by the women and healthcare professionals impacted on the women's reproductive behaviours and influenced the care they received. The prevailing perceptions of Type 2 diabetes were that it was a self-induced condition attributable to overeating and inactivity or that it was a condition of older age. The former perception was dominant in the women's accounts and was associated with negative self-image and feelings of shame, self-blame and guilt. Some women reported that they felt stigmatized and judged by family, friends and healthcare professionals for having developed Type 2 diabetes in their reproductive years. In consequence of these negative associations, many women reported non-disclosure of their diagnosis to others, including partners and family. Many women relayed how these negative perceptions influenced their health-seeking behaviours, with a tendency toward disengagement and inhibition when communicating with healthcare professionals about their reproductive intentions (Table 3).

The associations between obesity, older age and Type 2 diabetes were also evident in the healthcare professionals' accounts. Many healthcare professionals used negative labelling when referring to women with Type 2 diabetes, including the suggestion that they were generally 'non-compliant' with their care (Table 3). Some participants extended this to explain why these women were reticent to engage with pre-pregnancy care. Healthcare professionals were mainly of the opinion that women with Type 2 diabetes were not inclined to disclose their pregnancy intentions and just 'crash landed' in antenatal clinics. They considered the women to be ambivalent toward pregnancy planning, rather

than that they were not aware of the importance of pre-pregnancy care. Such perceptions seemed to impede the development of any constructive dialogue with women in respect of their reproductive healthcare needs.

The accounts of both the women and the healthcare professionals suggested that Type 2 diabetes is viewed as a lesser form of diabetes compared to Type 1 diabetes. The women's accounts revealed a belief that diabetes is only serious when insulin is required. The women also thought that Type 2 diabetes was a subordinate condition to Type 1 diabetes, leading some to believe that they were 'less important' than a person with Type 1 diabetes. A few women stated that if they had Type 1 diabetes, they would be less inclined to contemplate a pregnancy. Conversely, Type 2 diabetes was viewed as something they could get on with themselves and did not feature in their pregnancy plans (Table 3). This view was reinforced by the women's interactions with healthcare professionals, with most reporting that they had been told their condition was less serious than Type 1 diabetes.

Reproductive intention/potential

The desire to become pregnant was more important to some women than the need to consider pregnancy in the context of their diabetes prior to conception. Other women identified that they would prefer to sort their diabetes control out once they had become pregnant:

'*What's more important to me right now? Is it to have a child, or to have my sugar level at the correct level? I'm just gonna try and conceive anyway.*" (Dhir).

While in part this outlook reflected a lack of knowledge or understanding in respect of pre-pregnancy care requirements, it also reflected their personal desire to have a child either for themselves or to satisfy the expectations of their partner, family or wider community.

How healthcare professionals perceived the reproductive potential of women with Type 2 diabetes influenced how proactive they were in addressing pregnancy plans. Some healthcare professionals stated that they would not consider pregnancy needed to be discussed if they perceived the women as older with, in their view, limited reproductive potential (Table 4). Such perceptions meant that the healthcare professionals would be unlikely to address a woman's reproductive intention. Hence, while women with Type 2 diabetes and healthcare professionals have somewhat divergent perspectives on the potential for a pregnancy, both perspectives prejudice the likelihood of any constructive dialogue in respect of pregnancy intentions.

*C**ommunication** on reproductive issues*

Communication between healthcare professionals and women on reproductive issues was influenced by their respective agenda for, and expectations of consultations. The women reported that healthcare professionals often focused on general aspects of diabetes management, such as their diet and blood glucose levels, rather than reproductive issues. When conversations did include elements of pre-pregnancy care, the women stated that the healthcare professionals did not always respond in a way that they found meaningful or could understand. The women relayed that these conversations tended to emphasize their weight, diet and the need to optimize their glycaemic control; however, the women felt that these directives were not placed into the context of their pregnancy plans with any supportive explanation or intervention. Consequently, these conversations had negative connotations for the women, as they perceived these targets as being too challenging and that they were being judged for failing to achieve them, particularly in relation to their lifestyle.

The verbal interactions with healthcare professionals, as relayed by the women, suggested that each party had divergent objectives in respect of pregnancy. In general, the women felt that, during their consultations, the healthcare professionals focused on asking questions that enabled them to complete the template for Type 2 diabetes on their computers. The women described such consultations as

being 'tick-box' exercises, expressed in closed questions that failed to elicit their reproductive intentions or needs (Table 5).

The data also revealed that the women did not have a clear understanding of the importance or benefits of preparing for a pregnancy:

'*I wasn't making the changes because I didn't know why, if they had given me much more information I would have strived harder to achieve my goal*.' (Alice).

The accounts also suggested that there were often misconceptions in the women's understanding of the pre-pregnancy advice provided. One woman misinterpreted a comment by a healthcare professional that she would need to improve her glycaemic control prior to pregnancy as meaning that she would not be able to conceive:

'*The doctors told me if my blood sugars are not good, I cannot get pregnant*' (Daia).

The woman subsequently conceived with an elevated HbA_{1c} level. Similarly, conversations about folic acid did not always communicate the importance of taking it to protect the health of their baby, with one woman believing she was taking folic acid to enhance her ability to conceive:

'*She told me to take folic acid; it's to help pregnancy*.' (Cala).

These accounts suggest that, even when healthcare professionals addressed key elements of pre-pregnancy care, they did not elicit how the women were interpreting their recommendations or advice (Table 5). In consequence, the women were either unclear about or misunderstood what they needed to do in preparing for pregnancy.

Awareness of pre-pregnancy care guidelines

The healthcare professionals' accounts suggested a limited awareness and observation of current guidelines for pre-pregnancy care:

'*I haven't looked at these guidelines, because I didn't think I need it for my practice*.' (PN5).

While some of the healthcare professionals were aware of the guidelines, they had a limited understanding of their specific recommendations:

'*I haven't studied the guidelines—I'm sure they've got a lot of specifics in them, it's just, I don't deal in specifics.*' (PN1).

The accounts also indicated that the guidelines were used reactively, with healthcare professionals only considering them if they were unsure about care requirements, rather than to proactively inform their practice:

'*As a typical GP, if I had somebody I'd probably go and check the guidelines, but I don't check them all. I'm stimulated to do it by the patient in front of me*.' (GP6).

Accessing pre-pregnancy care

The reports of both the women and the healthcare professionals suggested that access to pre-pregnancy care is *ad hoc* in nature. There was no systematic identification of women with Type 2

diabetes, and healthcare professionals in primary care were often only prompted to think about pre-pregnancy care when there was some cue to do so, such as the presence of a partner or another child in the consultation. In the absence of a clear clinical pathway, healthcare professionals felt that there was a degree of fortuity in whether they would either refer a woman to pre-pregnancy care or provide such care themselves (Table 6). These comments were mirrored in the experiences of the women who found the process of accessing pre-pregnancy care to be circuitous and not clearly identified, and those who had accessed it thought it serendipitous rather than a systematic process (Table 6).

Previous pre-pregnancy care experiences

The few women who did experience pre-pregnancy care found it to be helpful and informative, with personalized targets which they were supported in achieving. They also appreciated the continuity of care within the pre-pregnancy service. Women perceived that in these services the specialist team was more accessible and had more time for them, in contrast to their experiences in primary care, which they recalled as being constrained in terms of time, accessibility and the quality of support provided (Table 7).

Discussion

The present study has identified how patient-, healthcare professional- and system-level factors mediate the pre-pregnancy support provided to women with Type 2 diabetes. The accounts of the women with Type 2 diabetes and the healthcare professionals provide converging explanations as to why so many women become pregnant without meeting current pre-pregnancy care criteria [4].

At the patient level there appear to be three interdependent phenomena that shape the reproductive behaviours of women with Type 2 diabetes. The first is their awareness, knowledge and understanding of the potential impact of Type 2 diabetes on pregnancy outcomes. The women's accounts concur with the findings of previous studies showing a low level of awareness with respect

to the importance of either preparing for pregnancy or avoiding pregnancy [12,15,17]. It was also evident that the women misinterpreted information they were given, increasing the risk of an unprepared pregnancy. In the UK there is currently no systematic approach for educating women with Type 2 diabetes on pregnancy, and it is not included in current structured education programmes for people newly diagnosed with Type 2 diabetes.

The second area relates to the feelings of shame the women have for developing Type 2 diabetes and their perception that it is not as important as Type 1 diabetes. Previous studies in people with Type 2 diabetes have identified that shame and stigma can impact negatively on patient activation and self-management [18–20]. The women's accounts suggested that these negative emotions led some to avoid discussing their diabetes with family members and healthcare professionals. This concurs with previous studies, which have found that women with Type 2 diabetes are reluctant to disclose or discuss their diabetes in their personal relationships [19,21]. These perceptions seemed to attenuate the women's willingness to discuss their reproductive intentions and needs.

The third phenomenon to emerge was a sense of ambivalence to pregnancy in the context of diabetes, which was related to the belief either that their diabetes was not serious or that pregnancy itself was more important than considering their diabetes. These were also related to misconceptions on the women's part, for example, that they would not be able to conceive because they had diabetes. This finding aligns with a previous study, which identified that women did not consider becoming pregnant with diabetes as important or that diabetes might in some way delay or prevent them from becoming pregnant [22]. Clearly such ambivalence is a potentially significant impediment to engaging women with Type 2 diabetes in pre-pregnancy planning, increasing the risk of an unprepared for pregnancy.

Overall, these data suggest that a more proactive approach is needed both to support women in developing a more positive awareness of becoming pregnant while living with Type 2 diabetes and to provide behavioural support to enable them to prepare for a pregnancy. Given that previous interventions providing information alone have only had a modest impact on the uptake of pre-pregnancy care [10,11,23,24], it may be better to develop behavioural approaches that help women identify the benefits of engaging in pre-pregnancy care for themselves and their babies. Such approaches should also address the underlying beliefs and negative emotional constructs that encourage avoidance and ambivalence with regard to women's reproductive intentions.

The study also identified that the interactions between healthcare professionals and women have an important impact on whether and how reproduction is attended to in clinical consultations. The data from both women and the healthcare professionals suggested that reproductive matters were not routinely considered in clinical care. A key explanatory factor, emphasized by the healthcare professionals and confirmed by the women, was that consultations in primary care were driven by meeting the general diabetes management criteria in which reproductive health does not currently feature [25]. The primary care-based professionals felt that they did not have the time or resources to address pregnancy in diabetes nor were they familiar with pre-pregnancy requirements. The lack of priority given to pre-pregnancy care in primary care settings may be reinforced by the assumption that it is the role of specialist diabetes teams to provide such care; however, access to such provision is contingent on the primary care professional referring women. It is important that there is a systematic approach in primary care to identifying women and that there are clear referral pathways. Furthermore, irrespective of whether a women intends to become pregnant, if the number of unplanned pregnancies is to be reduced, it is equally important to support women who do not wish for pregnancy to avoid it with effective contraception. At some level, therefore, it is essential that primary care professionals elicit and respond to the reproductive intentions of these women; hence, providing some level of pre-pregnancy management (including contraception) in primary care with

support from intermediate and specialist teams may be the optimum way to reduce unplanned pregnancies.

These data also show that if primary care professionals are to be responsible for the pre-pregnancy care of women with Type 2 diabetes, there needs to be better educational and healthcare system support. As previous intervention studies incorporating education and electronic prompts targeting primary care professionals have only achieved modest increases in pregnancy planning [10,11,23,24], it may be that in order to activate their engagement it will be necessary to incentivize the delivery of reproductive healthcare as part of the Quality Outcomes Framework [26], along with established diabetes care processes, as one GP indicated, 'You're financially incentivized to spend your time looking at things that do not include pre-pregnancy advice for women with Type 2 diabetes'.

The priority given to reproductive support by healthcare professionals may also be influenced by their underpinning views of this population of women. The accounts revealed that views held by healthcare professionals of women with Type 2 diabetes, particularly in relation to age and obesity, may subconsciously impede the likelihood of them eliciting or attending to women's reproductive intentions. It has been previously reported that obesity can negatively mediate healthcare professionals' interactions with patients [27,28], with prevailing stereotypes including: limited willpower, laziness, emotional instability, and being to blame for their weight [19,29–31]. Given that the women themselves harbour negative thoughts about themselves, developing a non-judgemental and affirmative approach to the conversations that take place with women with regard to their reproductive needs may help encourage them to engage in pregnancy planning.

A feature of this study was that it was undertaken in an inner-city context with high levels of deprivation and ethnic diversity; therefore, the findings may not reflect the views and experiences found in other settings. It is important to recognize, however, that it is in such areas that the proportion of women affected by Type 2 diabetes is greatest. In parts of London, for example, 70% of

pregnancies in women with pre-existing diabetes occur in women with Type 2 diabetes [5]. The high proportion of women of black and Asian ethnicity in the present study also reflects the higher incidence of Type 2 diabetes observed in women of reproductive age in these ethnic groups.

Most of the primary care professionals interviewed had a special interest in diabetes which may have biased the primary care accounts. However, it is likely that any such bias would mean that the challenges and limitations revealed in their accounts would be amplified in those without an interest in diabetes.

An additional limitation was that the study did not include maternal care professionals; their inclusion may have added additional perspectives, and future studies should consider this.

In conclusion, the present study suggests that there are significant deficits in the promotion and provision of pre-pregnancy care for women Type 2 diabetes, increasing their risk of an unplanned pregnancy. Future strategies need to consider: raising awareness about the need for pre-pregnancy care for women Type 2 diabetes; incorporating reproductive healthcare into education programmes at diagnosis and throughout the trajectory of their routine follow-up care; how primary care professionals can be better supported to positively elicit the reproductive intentions of women with Type 2 diabetes in a manner that is congruent with effective pre-pregnancy planning behaviours; and incorporating decision-making support tools and prompts within the care systems to initiate and reinforce pre-pregnancy care for women with Type 2 diabetes.

Competing interests

None declared.

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References

1. Coustan DR. *Medical Management of Pregnancy Complicated by Diabetes,* 5th edn. Alexandria: American Diabetes Association, 2013.

2. Berry DC, Boggess K, Johnson QB. Management of pregnant women with type 2 diabetes mellitus and the consequences of fetal programming in their offspring. *Curr Diab Rep* 2016; **16**:36.

3. Macintosh MC, Fleming KM, Bailey JA, Doyle P, Modder J, Acolet D *et al.* Perinatal mortality and congenital anomalies in babies of women with type 1 or type 2 diabetes in England, Wales, and Northern Ireland: population based study. *BMJ* 2006;**333**:177.

4. National Institute for Health and Care Excellence. Diabetes in pregnancy: management from preconception to the postnatal period. 2015. NICE guideline (NG3). Available at https://www.google.co.uk/#q=nice+pregnancy+diabetes+2015&spf=73. Last accessed XX Xxxx XXXX.

5. National Health Service (NHS) Digital. National Pregnancy in Diabetes (NPID) Audit Report 2016. 2017. Available at https://www.hqip.org.uk/resource/national-pregnancy-in-diabetes-audit-report-2016/#.XGqnTRG7I6. Last accessed XX Xxxx XXXX.

6. Feig DS, Hwee J, Shah BR, Booth GL, Bierman AS, Lipscombe LL. Trends in incidence of diabetes in pregnancy and serious perinatal outcomes: a large, population-based study in Ontario, Canada, 1996-2010. *Diabetes Care* 2014; **37**:1590–1596.

7. Pearson D, Kernaghan D, Lee R, Penney G. The relationship between pre-pregnancy care and early pregnancy loss, major congenital anomaly or perinatal death in type I diabetes mellitus. *BJOG* 2007; **114**:104–107.

8. Wahabi HA, Alzeidan RA, Bawazeer GA, Alansari LA, Esmaeil SA. Preconception care for diabetic women for improving maternal and fetal outcomes: a systematic review and meta-analysis. *BMC Pregnancy Childbirth* 2010; **10**:14.

9. Callec R, Perdriolle-Galet E, Sery GA, Morel O. Type 2 diabetes in pregnancy: Rates of fetal malformations and level of preconception care. *J Obstet Gynaecol* 2014; **34**:648–649.

10. Egan AM, Danyliv A, Carmody L, Kirwan B, Dunne FP. A prepregnancy care program for women with diabetes: effective and cost-saving. *J Clin Endocrinol Metab* 2016;**101**:1807–1815.

11. Yamamoto JM, Hughes DJF, Evans ML, Karunakaran V, Clark JDA, Morrish NJ *et al*. Community-based pre-pregnancy care programme improves pregnancy preparation in women with pregestational diabetes. *Diabetologia* 2018;**61**:1528–1537.

12. Forde R, Patelarou EE, Forbes A. The experiences of prepregnancy care for women with type 2 diabetes mellitus: a meta-synthesis. *Int J Womens Health* 2016;**8**:691.

13. Ritchie J, Lewis J, Nicholls CM, Ormston R. *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London: Sage, 2014.

14. Malterud K, Siersma VD, Guassora AD. Sample size in qualitative interview studies: Guided by information power. *Qual Health Res* 2016; **26**:1753–1760.

15. Doody O, Noonan M. Preparing and conducting interviews to collect data. *Nurse Res* 2013;**20**:28–32.

16. Murphy HR, Temple RC, Ball VE, Roland JM, Steel S, Zill-E-Huma R *et al.* East Anglia Study group for Improving Pregnancy Outcomes in women with Diabetes (EASIPOD). Personal experiences of women with diabetes who do not attend pre-pregnancy care. *Diabet Med* 2010; **27**:92–100.

17. O'Higgins S, McGuire BE, Mustafa E, Dunne F. Barriers and facilitators to attending pre-pregnancy care services: the ATLANTIC-DIP experience. *Diabet Med* 2014;**31**: 366–374.

18. Browne JL, Nefs G, Pouwer F, Speight J. Depression, anxiety and self-care behaviours of young adults with Type 2 diabetes: results from the International Diabetes Management and Impact for Long-term Empowerment and Success (MILES) Study. *Diabet Med* 2015;**32**(1):133–140.

19. Browne JL, Ventura A, Mosely K, Speight J. 'I call it the blame and shame disease': a qualitative study about perceptions of social stigma surrounding type 2 diabetes. *BMJ Open* 2013; **3**: e003384.

20. Link BG, Phelan JC. Conceptualizing stigma. *Ann Rev Sociol* 2001;**27**:363–385.

21. Singh H, Cinnirella M, Bradley C. Support systems for and barriers to diabetes management in South Asians and Whites in the UK: qualitative study of patients' perspectives. *BMJ Open* 2012;**2**:pii: e001459.

22. Spence M, Alderdice FA, Harper R, McCance DR, Holmes VA. Education and psychological aspects an exploration of knowledge and attitudes related to pre-pregnancy care in women with diabetes. *Diabet Med* 2010;**27**:1385–1391.

23. Murphy HR, Roland JM, Skinner TC, Simmons D, Gurnell E, Morrish NJ *et al.* Effectiveness of a regional prepregnancy care program in women with type 1 and type 2 diabetes: benefits beyond glycemic control. *Diabetes Care* 2010;**33**:2514–2520.

24. Willhoite MB, Bennert Jr HW, Palomaki GE, Zaremba MM, Herman WH, Williams JR *et al.* The impact of preconception counseling on pregnancy outcomes: The experience of the Maine diabetes in pregnancy program. *Diabetes Care* 1993;**16**:450–455.

25. Murphy HR, Bell R, Dornhorst A, Forde R, Lewis-Barned N. Pregnancy in Diabetes: challenges and opportunities for improving pregnancy outcomes. *Diabet Med* 2018;**35**: 292–299.

26. Doran T, Kontopantelis E, Reeves D, Sutton M, Ryan AM. Setting performance targets in pay for performance programmes: what can we learn from QOF? *BMJ* 2014; **348**: g1595.

27. Mold F, Forbes A. Patients' and professionals' experiences and perspectives of obesity in health-care settings: a synthesis of current research. *Health Expect* 2013;**16**:119–142.

28. Sikorski C, Luppa M, Glaesmer H, Brähler E, König HH, Riedel-Heller SG. Attitudes of Health Care Professionals towards Female Obese Patients. *Obes Facts* 2013;**6**:512–522.

29. Puhl RM, Heuer CA. The stigma of obesity: a review and update. Obesity. 2009;17(5):941–964.

30. Cossrow NH, Jeffery RW, McGuire MT. Understanding weight stigmatization: a focus group study. *J N Educ* 2001;33(4):208–214.

31. Friedman KE, Reichmann SK, Costanzo PR, Zelli A, Ashmore JA, Musante GJ. Weight stigmatization and ideological beliefs: relation to psychological functioning in obese adults. *Obes Res* 2005;**13**:907–916.

Table 1 Participant characteristics (women with Type 2 diabetes)

Characteristic	All 1.1.1.1.1.1 *n*=30	PPC exposure 1.1.1.1.1.2 *n*=11	No PPC exposure 1.1.1.1.1.3 *n*=19
Age, years	37 (25–44)	40 (32–43)	36 (25–44)
Duration of diabetes, years	5.5 (1–15)	8 (1-15)	4 (1–13)
HbA_{1c}, mmol/mol	57 (40–108)	58 (40–91)	70 (70–108)
HbA_{1c}, %	7.4 (5.8–12)	7.5 (5.8–10.5)	8.6 (7.3–12)
BMI, kg/m^2	34.9 (20.4–47.9)	34.2 (20.4–43.6)	35.3 (21.1–47.9)
Reproductive status, *n* (%)			
Pregnant	8 (27)	0	8 (100)
No contraception	14 (46)	6 (43)	8 (57)
Contraception	8 (27)	5 (63)	3 (37)
Adverse obstetric events, *n*			
Spontaneous abortion	8	3	5
Stillborn at term	3	2	1
Ectopic pregnancy	2	0	2
Relationship status, *n*			
Single	7	1	6
In a relationship	23	10	13
Ethnicity, *n*			
Asian	8	4	4
Black	16	6	10
White	6	1	5

Highest education attainment, *n*			
Secondary school	15	3	12
Higher Education award	15	8	7
IMD quintile[†], *n*			
1 (least deprived)	0	0	0
2	3	1	2
3	6	3	3
4	14	5	9
5 (most deprived)	7	2	5

IMD, Index of Multiple Deprivation; PPC, pre-pregnancy care.

Data are median (range), unless otherwise indicated.

*Healthy weight, BMI 18.5–24.9 kg/m^2; overweight, BMI 25–29.9 kg/m^2; obesity grade I, BMI 30–34.9 kg/m^2; obesity grade II, BMI 35–39.9 kg/m^2; obesity grade III, BMI ≥40 kg/m^2.

[†]IMD score range quintile groups, 1 (Least deprived) - 5 (most deprived)

Table 2 THEME: lack of visibility of pre-pregnancy care in routine Type 2 diabetes care

Women with Type 2 diabetes	
Sub-theme	**Data excerpt (participant pseudonym)**
PPC absent in routine care and education	*I didn't really get any help, no, because they never asked me if I was trying for a baby, I was never asked, did I want to get pregnant* (Cala, no PPC) *After Type 2 diabetes was diagnosed I went for a programme called DESMOND* [structured education programme]... *So I asked if I can still get pregnant as I desperately wanted a baby and I was told yes, but that was it, I wasn't given any explanation as to how to go about it, they didn't talk about pregnancy and diabetes at all* (Ava, PPC) *They* [healthcare professional in antenatal clinic] *asked, had you been going to the clinic about planning a pregnancy and I said 'what?' - I didn't know there was such a thing … that was the first I'd heard about it* (Carol, no PPC)
Time pressure in consultation	*When you go to see your doctor, you get about 5 or 10 minutes at the most, per appointment, isn't it? Unless I was to raise the question, they wouldn't, give the information freely, because they're wanting to go through other things* (Dara, no PPC).
Healthcare professionals	
Sub-theme	**Data excerpt (participant pseudonym)**

PPC not identified in routine care and education	*I'm going to be brutally honest – if somebody said to me, 'Oh, we're going to ask every woman who's diabetic about contraception or pre-pregnancy care before they get pregnant, and you get paid for it,' I would remember to do it, which is awful because – that's the way things work with target-driven stuff* (PN3). *Actually I hadn't thought about it until you asked me – we don't talk about it* [PPC] *when women are newly diagnosed, there isn't anything in DESMOND* [structured education programme] *about pregnancy at all which is interesting 'cause we do stuff for men* (DSN PC1).
Reliance on women voicing intention	*I don't give them support until they come to me and say, 'Actually, we're thinking of trying for a family,' which is interesting – it's more reactive, really* (GP3).
Clinical recording systems	*I mean it wouldn't be specifically coded as pre-pregnancy advice; it would probably be 'discussed family planning' just in free text, but then we can't audit that* (GP1).

DSN PC, diabetes specialist nurse intermediate care (community-based); GP, general practitioner; PN, practice nurse; PPC, received pre-pregnancy care; no PPC, did not receive pre-pregnancy care.

Table 3 THEME: perceptions of Type 2 diabetes

Women with Type 2 diabetes	
Subtheme	**Data excerpt (participant pseudonym)**
A self-induced condition	*I think society generally will just say, 'Well, if you're under 40 and you've been diagnosed, with Type 2 diabetes, that must be because of your own fault,' and generally, it is, anyway* (Dhir, no PPC).
Feelings of shame, self-blame	*Only certain people actually know I'm diabetic. Even family wise, I haven't really told them that I am diabetic, because I just think that there's, like, a stigma to being diabetic, and being quite young, especially if you've got Type 2, because in their mind, that's your own fault* (Dana, no PPC).
Feeling judged	*You don't really want to have to discuss it with other people, unless you really have to. I don't want to have to hear, 'Oh, well, why are you diabetic at your age? How has this, kind of, happened? You know, and what are you doing to maintain a healthier lifestyle, what are you doing to make changes?*' (Daisy,no PPC)
A lesser form of diabetes	*Like in my case, if I was Type 1 diabetic it would impact on my decision* [to plan a pregnancy] *because Type 1 is quite severe, it's quite like serious. But Type 2 you can – you have a little bit of hope that you can manage your sugar with diet or with the help of like tablets and things like that* (Balou, PPC).

Healthcare professionals	
Sub-theme	**Data excerpt (participant pseudonym)**
Negative constructs about Type 2 diabetes	*I would say that people with Type 2 don't recognise the importance of what we're saying with regards to their diabetes; they're in denial that there's going to be any issues….so it's about making sure they comply with their medication, attend their appointments which of course they often don't* (PN 8)
Women's understanding or ambivalence	*I mean often with these people they don't really understand how important Type 2 diabetes is. Some of them seem to think it's a trivial condition that they can just take a few tablets for, so they don't see pre-conception as relevant to them* (GP6). *Despite our efforts we still have a large number of people with diabetes crash landing on services when they become pregnant, there's no planning phase for them* (GP4). *Well we tell them, yes – its Type 2 they've got, so if they just lose weight and take the medication we give them they should be able to self-manage it* (GP4).

Obesity emphasis	*With Type 2 diabetes people will tend to be on the large – that's a bit unfair of me, but they are on the larger side. So it's the weight that I would just automatically address with them* (DSN SC2).

DSN SC, xxx; GP, general practitioner; PN, practice nurse; PPC, received pre-pregnancy care; no PPC, did not receive pre-pregnancy care.

Table 4 THEME: reproductive intention/potential

Women with Type 2 diabetes	
Sub-theme	**Data excerpt (participant pseudonym)**
Cultural expectations	*They've told me to use contraception, but I can't pay attention to that because I want a baby, I want a baby by all means. I can't stay like this without a child – I'm the only one in my family without children* (Anne, PPC).
Pregnancy as a priority	*I decided that I felt like I wanted to try for another baby, so I didn't take the pill as regularly as I should* (Claire, no PPC).
	I said – in my mind, I do not tell them [healthcare professionals] – *I said, instead of doing that* [commencing diabetes medication] *right now, let me just have a go for a baby* (Cayla, no PPC).
	I've been trying – any opportunity to actually get pregnant. I think, if someone just told me to avoid pregnancy now, I don't think I would. I don't know if I'd take that on board (Darlene, no PPC).
Partner views	*My husband was a bit scared of these contraception – he said you gain weight and these things. I never had time to do a coil contraception, but anyway we needed a baby* (Badri, PPC).

Healthcare professionals	
Sub-theme	**Data excerpt (participant pseudonym)**
Age and reproduction	*People look different ages, don't they? With **T**ype 2, I mean, I know we've got the age in front of us on the screen but sometimes you'll have someone sitting in front of you that actually looks quite old and they're not and you sort of assume that they must be past the menopause and everything* (DSN PC4). *I think once you're in a clinic situation then certain patients of a certain, you know, cut-off and people with Type 2 are often older than that child-bearing age, aren't they?* (DSN PC2)

DSN PC, diabetes specialist nurse intermediate care (community-based); PPC, received pre-pregnancy care; no PPC, did not receive pre-pregnancy care.

Table 5 THEME: communication on reproductive issues

Women with Type 2 diabetes	
Sub-theme	**Data excerpt (participant pseudonym)**
Divergent objectives	*If the nurses doing the annual reviews, has a Type 2 woman of child-rearing age they may wish just to drop pre-pregnancy care into the conversation; you know, when they ask you if you're depressed and having suicidal thoughts, which they seem to ask you every single year, because I know they have to* (Beth, PPC).
Tick-box approach	*They* [healthcare professionals] *focus on my diabetes, not about me wanting to have a child, but about my diabetes* (Amy, PPC).
	If they ask if you have any sort of contraception and what you're using, once you say yes, that's it – it just goes on to the next question on their list, nothing about if you're thinking about pregnancy (Emily, no PPC).
Understanding the rationale for PPC	*I have a very good GP, she knows me quite well, but because I didn't ask her for any contraception she may think she doesn't have to talk with me about it. This is what I guess* (Denes, no PPC).
	They were just saying to tell them if I was thinking of a baby – they didn't tell me what the help would be, you know, it was just me telling them (Eber, no PPC).

Healthcare professionals	
Sub-theme	**Data excerpt (participant pseudonym)**
Constrained agenda	*In general practice because you have a short amount of time, I think that makes it hard because you tend to concentrate on what you need to get done* (GP2). *Pre-conceptual and planning tends to go lower on your prioritisation list because you're dealing with the here and now* (GP1). *With diabetes and pre-conception care it is very much preventative medicine. People don't think about problems that may happen. They would rather deal with problems that are happening, so that's something inherent* (GP3). *I'm not going to do the specialized pre-conception care, it would be a specialist that would do that – so it really is about me identifying them* [women with Type 2 diabetes] (GP2).
Tick-box approach	*No matter what really, we always go back to diet, exercise, and blood sugar control. So it is about looking at their lifestyle in order to do this, so that's what we stress to them* (PN6).

Explaining PPC	*I mean often times we make decisions in our heads don't we, and not necessarily explain why we are doing particular things, so like with prescribing, I'm not going to start explaining why I'm giving one drug over another, but I know that some are not suitable for pregnancy or such like* (GP4).

GP, general practitioner; PN, practice nurse; PPC, received pre-pregnancy care, no PPC, did not receive pre-pregnancy care.

Table 6 THEME: accessing pre-pregnancy care

Women with Type 2 diabetes	
Sub-theme	**Data excerpt (participant pseudonym)**
Clarity of PPC care-pathway	*So I talked to the nurse, and if you want to be pregnant she will pass me on to the doctor – she'll have to book an appointment with the doctor. Then I have to talk with him and he'll refer me to the hospital* (Daisy, no PPC). *Once, the GP did say that if I become pregnant there will be is a special department or clinic that will look after me, but nothing about before* (Chara, no PPC). *I was told if I want to come to pre-pregnancy clinic there is some kind of system; so first I should go to a GP who will send the referral and it will then take 2 to 4 weeks to get an appointment* (Bella, PPC).
Enabling access to PPC	*I started talking to my GP about getting pregnant, he immediately told me I have to control my HbA_{1c} first. No further discussion, it wasn't ever about pregnancy, just I won't be referred to a specialist until I achieve my HbA_{1c} first* (Alice, PPC). *One of the nurses in the eye clinic asked me about it, so I said I wanted to have one more child. She put me forward for the*

	preconception but I wouldn't have known without her question (Danni, no PPC).
Healthcare professionals	
Sub-theme	**Data excerpt (participant pseudonym)**
Fortuity in Identifying women for PPC	*I guess if they came into the surgery with children I might be alerted more* (GP1). *If someone's 47 then you feel a bit silly discussing pre-conception, so it's tricky to know when to discuss it* (CE1).
Clinical delegation	*I don't think I see them because our diabetic women are quite well followed up by our practice nurses and pre-pregnancy stuff would be with the nurses usually* (GP6). *I'm not an expert on it but I just know the basics and I think if they want an in-depth knowledge they'd have to go to a proper pre-pregnancy clinic, so we would have to refer them* (DSN PC2).

CE, consultant endocrinologist; DSN PC, diabetes specialist nurse intermediate care (community-based); GP, general practitioner; PPC, received pre-pregnancy care; no PPC, did not receive pre-pregnancy care.

Table 7 THEME: previous pre-pregnancy care experiences

Women with Type 2 diabetes	
Sub-theme	**Data excerpt (participant pseudonym)**
Care continuity	*If you come to the pre-pregnancy clinic you will get the result then and there, like the HbA_{1c}, there won't be any delay. If you go to the GP it will take 1 or 2 weeks, and we should follow it up – and I could call the pre-pregnancy clinic any time if I have any problem* (Bella, PPC).
Patient engagement	*For me the pre-pregnancy clinic was positive because it wasn't like, if I said 'I'm thinking of getting pregnant' the response would be 'Oh no, no, no, you cannot get pregnant. No, it's not good for you when you're Type 2.' It wasn't like that, it was an explanation that I can be pregnant, Type 2 diabetes doesn't mean that there's things you cannot do, or you shouldn't do. The pre-pregnancy clinic has been positive, they really explained things to me that I wasn't aware of before* (Balou, PPC).
Care quality	*It's interesting, actually, being seen at my GP and being seen at the pre-pregnancy clinic, because actually, my GP, when I contacted him and said, 'I need a prescription for folic acid, 5 mg,' he went, 'Oh, gosh, why do you need that much?' And I was, like, 'Well, because I'm diabetic.' And he actually had to go away and look it up and he called me back and he said, 'I am very sorry, you are quite right.', and diabetes is one of his areas that he's interested in* (Beth, PPC).

PPC, received pre-pregnancy care.